

SPECIAL ISSUE

Genetic counseling in the time of COVID-19: The Philippine experience with telegenetics

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Abstract

The COVID-19 pandemic poses a significant challenge to healthcare professionals and health systems around the world, most notably the disruption of its service delivery. The typical work setting for most genetic counselors (GCs) is in a clinic or hospital. However, during the COVID-19 pandemic, to help prevent the further spread of the virus, clinics and hospitals have restricted non-urgent in-person delivery of healthcare services, including genetic counseling. Patients' access to genetic counseling services has thus been limited, which prompted GCs in the country to utilize an alternative way to provide counseling through telegenetics. With the expansion of genetic services in the country, including the full implementation of expanded newborn screening, there is an increasing demand for genetic counseling and a growing need for telegenetics.

KEYWORDS

COVID-19, experience, genetic counseling, genetic counselors, genetic services, telegenetics, Philippines

2 | INTRODUCTION

COVID-19 is a disease caused by the novel coronavirus now known as severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The first human cases were reported at Wuhan, China, in December of 2019 and subsequently spread to nearly every country leading the World Health Organization (WHO) to declare the outbreak as a pandemic or a Public Health Emergency of International Concern (WHO, 2020).

The COVID-19 pandemic poses a significant challenge to healthcare professionals and health systems around the world, most notably the disruption of service delivery. Genetic counselors (GCs), as part of the healthcare team, play an important role in providing genetic services by helping patients and/or families "understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease", (Resta et al., 2006). Genetics and

genetic counseling have become integral to health care as we learn more about genetic risks for disease (Bruder, 2020). The typical work setting for most GCs is in a clinic or hospital. However, during the COVID-19 pandemic, to help prevent the further spread of the virus, clinics and hospitals have restricted in-person delivery of healthcare services that are not deemed urgent, including genetic counseling. Patients' access to genetic counseling services has thus been limited, which prompted GCs to utilize an alternative way to provide counseling through telegenetics.

An article from Pagliuzzi et al. (2020) described their genetic counseling experience in Tuscany, Italy, when the pandemic hit. It was widely known that Italy was one of the hardest-hit countries during the pandemic. A pediatric tertiary hospital in Tuscany stratified their scheduled visits and assessed which cases would be seen via face-to-face and which would be seen via telemedicine. All prenatal visits were face to face since the patient still had to go the hospital for

other procedures, aside from the genetics consultation, whereas all postnatal visits were switched to telemedicine (Pagliuzzi et al., 2020).

A study published by Bergstrom et al. in October 2020 assessed the professional impact of the COVID-19 pandemic on genetic counselors and evaluated how genetics service delivery models changed in New York. The study compared the clinic structure, telegenetics use (either video and/or telephone consultations) and acceptability as well as professional practices before and during the pandemic. An anonymous survey of 165 GCs in New York State revealed that prior to the pandemic, in-person (49%) and a combination of phone consultation and in-person (22%) were the most common consultation types. However, during the pandemic, the most common consultation type were telephone and video conferencing (39%) (Bergstrom et al., 2020).

A paper by Norman et al. (2020) described the Canadian experience in a cancer genetics center, which shifted to virtual services following the breakout of the COVID-19 pandemic. In their experience, there were fewer referrals from referring physicians due to the decreased demand for tertiary care services, hence lower number of new patients were seen. However, the center was able to maintain the regular number of appointments scheduled from pre-virtual to virtual care. The authors described that good institutional support, robust technological solutions, and teamwork among staff to make the virtual services and experience work for their patients were some of the elements that made them successful in delivering quality virtual genetic and genetic counseling services (Norman et al., 2020).

Adopting telegenetics has its challenges including lack of proficiency with technology by both patients and healthcare providers, limited social interaction, and limited ability to perceive non-verbal cues (Zierhut et al., 2018). Logistical difficulties are another challenge, which include difficulty in obtaining consent, inability to incorporate a secondary healthcare provider in the consultation, longer time between pretest counseling and sample collection, difficulty in sample collection for genetic tests, and increased waiting time from sample collection to results disclosure (Bergstrom et al., 2020; Mahon, 2020; Norman et al., 2020). Nevertheless, the benefits of telegenetics are many. For example, patients have expressed appreciation of telemedicine since it enabled them to consult with their physicians, while being in the safety of their homes. It also lessened the need of the family to travel long distances, thereby providing consultations faster, decreasing the waiting time, and reducing the loss of time from work of the parents (Bergstrom et al., 2020; Mahon, 2020; Norman et al., 2020; Pagliuzzi et al., 2020; Zierhut et al., 2018). Furthermore, the majority of the participants have expressed their desire to continue to practice telegenetics even after the pandemic (Bergstrom et al., 2020).

With the expansion of genetic services in the Philippines, including the full implementation of expanded newborn screening (ENBS), there is an increasing demand for genetic counseling and a growing need for telegenetics. This paper describes the Filipino Genetic Counselors' telegenetics experience in the time of COVID-19, to provide improved telegenetics and counseling services, not only during emergency crisis, but also in the future.

What is known about this topic

There are numerous published articles on the experiences of other countries (mostly the developed ones), regarding their experiences in telegenetics especially during the pandemic. But not much is known about the developing countries' experiences.

What this paper adds to the topic

This paper intends to describe the Filipino Genetic Counselors' telegenetics experience in a time of COVID-19 to provide improved telegenetics and counseling services, not only during emergency crisis, but also in the future.

2.1 | Definition of terms

Telehealth and telegenetics are terms that are often used interchangeably (Zuniga, 2018). The former is defined by the U.S. Department of Health and Human Services (2016) as the interaction between provider and patient with the use of video and voice communication technologies. Telehealth covers all components and activities of health care including the healthcare system that are initiated through online and or telecommunications technology such as computers and mobile devices. It also includes the use of wearable devices and video conferencing that records and transmit vital signs that allows provider to provider communication. It is frequently used interchangeably with telemedicine that is described as the use of technologies and telecommunication systems to provide remote diagnosis or administer health care, that is, diagnostics, monitoring, and therapeutics to patients that are geographically separated from their providers (Mayo Clinic, 2020; NEJM Catalyst, 2020).

Telegenetics on the other hand is described as a telehealth tool for online genetic counseling, primarily initiated to improve access to genetics care in remote areas via videoconference or web-link, including visual and audio access (Cohen et al., 2013; Hilgart et al., 2012; Vrečar et al., 2017). Although telehealth has long been offered by genetic counselors as an option to their patients, it has become more of an acute need during the COVID-19 pandemic (Flanagan, 2020).

2.2 | The Philippines

The Philippines is an archipelago in South East Asia, covering an area of about 300,000 km². It is made up of more than 7,000 islands, divided into three major island groups—Luzon, Visayas, and Mindanao. The country is the 12th most populous country in the world, and 4th in Southeast Asia, with a population of 109 million (World Fact Book, 2020). There are various ethnolinguistic groups, Tagalog and Cebuano being the majority. Catholicism is the predominant religion, with 81% of the citizens being Roman Catholics. Filipino and English

are the two official languages (World Pop Rev, 2020). Gross domestic product (GDP) in the Philippines was worth 376.80 billion US dollars in 2020 (World Bank, 2020).

In the Philippines, where there is a shortage of clinical geneticists and genetic counselors, a Telegenetics Referral System was previously proposed as an alternative to an in-person consultation (Padilla et al., 2011). However, genetic counseling and telegenetics services have remained a challenge in numerous islands given the language barriers, literacy level, and bioethical, religious, and sociocultural needs of Filipino patients and their families.

3 | GENETIC COUNSELING IN THE PHILIPPINES

Genetic counseling is the "process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease" (Resta et al., 2006). The genetic counselor roles include patient and family medical history taking, risk assessment and counseling, and provision of psychosocial support to patients and their family members (Laurino et al., 2017). The genetic counselor to population ratio in the Philippines is 1:16, 390,000, while the clinical geneticist to population ratio is 1:10, 930,000 (Padilla & Cutiongco-de la Paz, 2013; Philippine Statistics Authority, 2016).

Given the demand for genetic counselors in the country, the Master of Science in Genetic Counseling (MSGC) program was instituted at the University of the Philippines Manila in 2011 (Laurino & Padilla, 2013). The program serves a vital role in implementing and expanding genetic counseling services in the country. Genetic counseling services in the Philippines are primarily available in government tertiary level facilities, but there are plans to improve access to genetic counseling services in the periphery through the continuity clinics attached to the National newborn screening program (Padilla et al., 2003, Padilla & Cutiongco-de la Paz, 2013).

Currently, some GCs are employed in newborn screening centers (NSCs) and provide in-person delivery of genetic counseling services and telegenetics services. Clinical genetic counseling services are also provided by medical geneticists, genetic fellows, and genetic counseling students while supervised by clinical preceptors (Laurino et al., 2017). There is a continued increase in demand for genetic counseling services in the country because of the expansion of the Philippine newborn screening program and various public health genetics programs, including the Birth Defects Surveillance Project, Telegenetics Referral System, and the establishment of the Philippine Genome Center (Padilla & Cutiongco-de la Paz, 2013).

Language barriers, literacy level, cultural factors, and the complex nature of genetic information made genetic counseling a challenge in the Philippines (Cutiongco-de la Paz et al., 2019). In addition, compromised access to health services in remote areas is also a pressing concern. Delivery of medical genetic services remains a challenge in both private and public sectors, and the Telegenetics Referral System was thus proposed to help bridge the gap in the delivery of

genetics and genetic counseling services (Padilla & Cutiongco-de la Paz, 2013).

4 | OUR EXPERIENCE WITH TELEGENETICS DURING THE PANDEMIC

4.1 | Pre-pandemic versus pandemic situation

Before the pandemic, from January 2019 to February 2020, 275 patients were counseled—wherein 15% of these (43 patients) were counseled via telegenetics (video or phone call). These patients were counseled via telegenetics because of their geographical location. The rest of the patients were seen at the clinic and counseled face to face. When the pandemic hit and a strict lockdown was enforced in the country, all counseling were shifted to telegenetics. From March 2020 to March 2021, a total of 519 patients were counseled either by video call or by phone call. We were able to accommodate more patients during the pandemic because more patients were able to access the service even if they live in far-flung areas. Also, since there was little or no travel time, for both the counselors and patients, it was possible to schedule more patients per day. Our experience with counseling via telegenetics is described below.

4.2 | Case scenario

A baby was diagnosed to have ornithine transcarbamylase deficiency (OTC) at the peak of COVID-19 lockdown in the country last March 2020. Referral and coordination between the attending physician, geneticist, and genetic counselor were mostly done via telephone and telegenetics. Genetic counseling and genetics education on OTC via Zoom were arranged with the parents after discharge. The smartphone was the only accessible device for the parents at that time since internet cafes with private cubicles were closed during the lockdown. Fortunately, the mobile signal and mobile internet in the area of the parents were stable and the session proceeded without any technical issues. Share screen was used during the counseling session using the smaller screen of the smartphone, although it is preferable that parents have access to a laptop/PC/tablet. The session continued for two hours in order to accommodate for the limited size of the phone screen. The small size of the screen makes it difficult for the parents to read the content of the slides. More time is needed to make sure that the parents can follow the discussion, zooming in if necessary, and to allow the parents time to process the information being showed to them.

4.3 | Access to telecommunications and use of social media

With COVID-19 lockdown and quarantine regulations in place all over the world, online and telephone counseling are among the most

adaptable solutions for healthcare providers, but it is not without caveats. Moreover, existing telecommunications infrastructure and services are usually limited to big cities and suburban regions, often-times with problematic services due to the volume of subscribers, legislative roadblocks, and the archipelagic nature of the country (Cigara, 2020; Rodriguez, 2020; Shahani, 2016).

According to the 2017 Digital Trends Report (Kemp, 2017), the Philippines is estimated to have 44% urbanization of its cities and municipalities, with 58% of the population, or 60 million people, having internet and social media access. Fifty-two percent of the population (about 54 million people) are active social media users on mobile devices. Eighty-eight percent of the Filipino population have access to mobile phones, but only 61% have access to smartphones capable of running apps such as Zoom and Skype. Unfortunately, access to a PC or laptop, which is ideal for telegenetics, drops down to 39%, and access to tablets is even lower at 25% (Kemp, 2017).

With the above statistics in mind, GCs in the Philippines need to adapt and capitalize on what is readily available and feasible for patients given the limitations of current conditions. Social media, particularly Facebook (FB), has changed the digital landscape of Filipinos (Kemp, 2017). By experience, our clients prefer to use FB messenger over text or email. Sending a private message in FB messenger is also sometimes more advantageous, given the poor coverage to some areas where text messages are impossible to receive, or can get lost or be delivered broken. FB messenger can assure that the complete message will be delivered once the client has access to the Internet or going to an area where there is signal access.

4.4 | Genetic counseling by video call

Apart from face-to-face counseling, genetic counseling by video call is an option for patients or families who cannot personally come to the clinic. In our practice, a mix of face-to-face interaction and telegenetics have been used since before the pandemic. Pretest counseling is conducted through face-to-face interaction, or sometimes by video call when a patient lives far away. Some of the families we have encountered choose this method because of their geographical location or their work schedules. Since the majority of genetics services are situated in urban areas, which is a big challenge for patients living in rural areas, telegenetics can help improve access. Video counseling and counseling by phone are commonly adopted for the convenience of either the patient or the counselor (Cohen et al., 2016).

At present, the process of providing genetic counseling by video call is the same as providing it face to face. The family pedigree is taken, and then the GC uses visual aids by using the 'share screen' option. Looking at the aids while listening to the GC's explanation can help increase the family's understanding of the genetic disorder, or the utility of the genetic test that may be presented, in cases of pretest counseling.

The video call platforms that we currently utilize are google Hangouts/google meet, zoom, and Skype. Facebook messenger can

also be used whether the patient or family is not familiar with those platforms.

A study by Gattas et al. (2001) noted another limitation, which is that telegenetics consultations work best when one-on-one because it is difficult to fit multiple family members on screen at the same time. We have the same challenge, since majority of the families we have counseled use smartphones that have smaller screens compared with computers or laptops. Usually, only the mother attends the session because of this limitation.

Another challenge for us is that some families have poor internet signals or do not have internet access at all. In these cases, we seek the assistance of the newborn screening centers or a nearby local health facility with internet access to accommodate the family for genetic counseling. Technical glitches also occur from time to time, for example, when the family is not able to view the visual aids through a shared screen, or when there are problems in the audio and the family is unable to hear the counselor very well. We resort to telephone counseling when these issues happen.

4.5 | Genetic counseling by telephone

In our practice, post-test counseling is usually done by telephone. When the pandemic began, we fully transitioned to telegenetics for the sake of safety. However, there are still quite a number of our patients who do not have access to a computer, laptop, and/or a smartphone that can handle video calls. There are also others who do not have stable Wi-Fi/internet access or do not have internet access at all because of their geographical location or financial constraints. The average Filipino family earns 26,000.00 Php (520 US\$) per month, but this varies depending on the geographical location. Family incomes can be as low as 13,000 Php (260 US\$) per month in the Mindanao area (Philippine Statistics Authority, 2018). For these patients, we have no other choice but to do the counseling by calling their mobile phones. Studies have shown that genetic counseling via phone call is also an effective way of delivering counseling services to patients who live far from genetic specialists (Kinney et al., 2014; Schwartz et al., 2014). It can provide a realistic way of giving comprehensive counseling to those who need it, thereby increasing access, and decreasing the cost for both patient and counselor (Platten et al., 2012).

Telephone counseling is certainly not without problems. We had an experience where the family of a child with alpha thalassemia was scheduled for post-test counseling on a particular date. However, the newborn screening nurse called us to ask whether we could accommodate the family that day and conduct the post-test counseling session by phone. Apparently, the family resides in an area where cellular phone signal is very weak. The mother had to go to the nearest town to get a signal and contact the nurse to inform her of their situation. In another case, a family did not own a mobile phone and had to borrow their neighbor's phone in order for the counseling to take place.

The strength of the mobile network can also present challenges with connections and comprehension. Some of our patients live in

mountainous regions where cellular network signal is weak. Sometimes our connection will be interrupted or dropped—it is not unusual to disconnect and reconnect multiple times over the course of one session. There are also times when the mother is the primary caregiver, and there is no other person available to hold the pediatric patient while we are talking. In cases such as these, the mother may be distracted by taking care of the patient and/or taking care of the other children, and thus, her full attention is not on our conversation. When given the option if they want to call us back when they are not busy, they will usually decline and say they want to continue the session now, since there is not really any other opportune time to do the counseling.

Another challenge with phone counseling is that we are unable to show visual aids that may assist in understanding of the disease. For example, when the baby is screen-positive and the family is recalled for blood collection for confirmatory testing, a 1-page brochure regarding the disease is given to them. When we call the family for counseling, we always ask whether they have read the brochure and whether they have it with them at the moment. If they have it with them, we request them to hold it while we are talking so we can go through it together. However, more often than not, they have not read the brochure, or they lost the brochure, in which case we are forced to provide genetic education and counseling through telephone, with no visual aids.

4.6 | Data privacy

In the Philippines, protection of data and information is a law, under the Data Privacy Act (DPA) of 2012. Section 21 states, 'All sensitive personal information maintained by the government, its agencies and instrumentalities shall be secured, as far as practicable, with the use of the most appropriate standard recognized by the information and communications technology industry' (National Privacy Commission, 2012). Genetic counseling sessions made through video calls are all done through secured video call platforms specifically Zoom, Google Hangout, Skype, and Facebook Messenger. These video conferencing platforms are all compliant with the DPA. These video conferencing platforms are also compliant with the existing laws and guidelines of the Philippine Department of Information and Communications Technology and of the National Privacy Commission.

Clinical data and sensitive information that is gathered during the genetic counseling sessions and follow-up are collected with patient consent and/or consent of their parents and legal guardian in accordance with the DPA Sec 12, 'The processing of personal information shall be permitted only if not otherwise prohibited by law and the data subject has given his or her consent' (National Privacy Commission, 2012). This information is in a form of electronic copies and/or paper-based data and is kept in a secured locker and computer, wherein the attending genetic counselor is the only one who has access.

After each genetic counseling session, patients and parents are reminded about their right to 'suspend, withdraw or order the blocking, removal or destruction of his or her personal information from

the personal information controller's filing system upon discovery and substantial proof that the personal information is incomplete, outdated, false, unlawfully obtained, used for unauthorized purposes or are no longer necessary for the purposes for which they were collected' and also 'Be indemnified for any damages sustained due to such inaccurate, incomplete, outdated, false, unlawfully obtained or unauthorized use of personal information' as indicated in the DPA Sec 16 (National Privacy Commission, 2012).

5 | FUTURE DIRECTIONS

As we reflect on our experience-based benefits in the past year, it is clear that telegenetics increased access to genetics experts in the country and will remain as a crucial option for clinical care delivery. This said, the Philippines's current system has systemic limitations (e.g., Internet connection, owning home computers / smartphones/tablets, technology know-how of patients) that need to be addressed to ensure that access is equitable to all patients. These challenging gaps will require advocacy efforts by a multi-specialty team (e.g., clinical experts, technology sector, and public health system) for success. This paper is the first step into examining the telegenetics capability of the country—by ascertaining barriers and limitations and creating solutions for the successful implementation of telegenetics service.

6 | CONCLUSION

Even before the COVID-19 pandemic, the delivery of genetic counseling services, conducted through a combination of face to face and video counseling, has been challenging for our country. During the COVID-19 pandemic, the Philippines was placed on a complete lockdown thereby prompting counseling services to shift purely to remote provision of services. During the pandemic, we have counseled 519 patients via telegenetics (March 2020–March 2021). This was a big increase from the pre-pandemic period (January 2019–February 2020), wherein we were able to counsel 275 patients—only 15% of which (43 patients) were counseled via telegenetics. Genetic counselors in the Philippines had to be innovative in order to ensure the continued delivery of genetic counseling services to the patients and their families. Telegenetics was employed as a primary mode of service delivery, including counseling via video call, mobile phone, and even through social media, particularly Facebook messenger. Advantages of adapting telegenetics in our practice include being able to reach patients from geographically isolated areas, less travel time, and reduced time off from work for parents. Disadvantages include longer GC sessions due to unstable Internet connection or mobile network signal and inability to access non-verbal cues from patients. The process and delivery of genetic counseling services in the country continue to evolve as we move toward the new normal brought about by the pandemic. This sharing of experiences is hoped to

contribute to policymaking and infrastructure development of the government to address the growing needs of its citizens and adaptation to telehealth and telegenetics.

AUTHOR CONTRIBUTIONS

Author Ma-Am Joy Tumulak made substantial contributions to the conception and drafting of the article. All of the authors made contributions to the drafting of the article. All authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Authors Ma-Am Joy R. Tumulak, Angela V. Pascua, Edbert Jasper M. Jover, Romer J. Guerbo, Graciela Mae R. Canoy, and Mercy Y. Laurino declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

No human studies were carried out by the authors for this article.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

DATA SHARING AND DATA ACCESSIBILITY

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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